

Raising Prostate Cancer Awareness in Black Communities



Information from Prostate Cancer UK (2018) indicates overall statistics that 1 in 8 men will be given a prostate cancer diagnosis. However, black men are more likely to be given a prostate cancer diagnosis within their lifetime with statistics rising to 1 in 4 men.

Most black men are unaware of this increased risk, so to help raise awareness within this group of men, Clare Waymont and Kelly Kusinski were invited to participate in a prostate cancer discussion at the Afro Caribbean Heritage Centre in Wolverhampton in June 2018.



With approximately 50 attendees the discussion was greatly received. Presentations were given from Tony Sealey who has recovered from prostate cancer and is now a prostate cancer ambassador, and Clare Waymont regarding how a prostate cancer diagnosis is made. Several patients gave insightful talks on their own prostate cancer journeys and we also were joined by the Nottingham black men prostate cancer support group (Friends and Bredrins of Prostate Cancer) Overall there was great enthusiasm to spread the word regarding prostate cancer and encouragement of men to participate in prostate cancer investigations.

Since this initial discussion, a small group of men have formed together to continue raising awareness and offer support to other black men. Information is displayed within the Heritage Centre and interviews and podcasts have been broadcast via Skyline Radio. Kelly Kusinski has attended one further event at the same venue and hopefully will be able to continue to support the needs of this group also.



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*"Wishing you all a very
Happy New Year for 2019"*

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Canal Boat Trip

The support group committee is planning a social event next summer on Sunday 7th July at 2pm. This will comprise of a canal boat trip and afternoon tea (approximate cost £10) departing from Norbury junction. If you are interested in coming along, please speak to Alison Littleford or any of the committee members.



Arrivals and Departures

Sadly, Mr Sur left the urology department earlier this year to take up a new life in Australia. Diane Lilley, Urology Nurse Practitioner has also taken up a palliative care post elsewhere. We are pleased to welcome a new Consultant Urologist, Mr Muthuveloe.



Mr David Muthuveloe

Mr Muthuveloe trained at Imperial College London and completed his specialist Urology training in the West Midlands.

His subspecialist interest is in the endourological treatment of stone disease with a particular interest in laser surgery and upper tract diagnostics. He is also trained in the management and treatment of complex stone diseases and percutaneous nephrolithotomy.

Mr Muthuveloe is keen to advance the diagnostic services for urological malignancy such as prostate and bladder cancer but also develop the service for BPH treatment with Urolift and HoLEP surgery.

During the course of his training Mr Muthuveloe spent a year performing clinical research at the University of Birmingham School of Cancer Sciences. This helped him advance his research skills and appreciate the importance of evidence based medicine to improve patient experience and outcome.

"...I grew up nearby and attended school in Wolverhampton, so I was thrilled to come back to my old stomping ground to help serve the people of Wolverhampton and its surrounding area."

Wolverhampton Prostate Cancer Support Group

Newsletter December 2018

Welcome to the latest newsletter from the Wolverhampton Prostate Cancer Support Group for the year 2019. Please note that meetings will continue at the new time of 1.45pm to 3.30pm at the Community Centre, Marsh Lane, Wolverhampton, WV10 6SE. Thank you to everyone who continues to support the group and attends the meetings. There is no membership fee or charge for attending meetings, so please continue to contribute to the raffles; we rely on monies raised to fund the meetings.

Dedicated to Derek Evans (1939-2018)

Past Chairman of Wolverhampton Prostate Cancer Support Group



New Programme for 2019

Here is the new programme for the next year's meetings. If there are any subjects of particular interest to you that do not appear on the programme, then please let Clare Waymont or the committee know.

Monday 28th January 2019
Charitable PSA screening events
(The Graham Fulford Charitable Trust)

Monday 18th March 2019 – RAFFLE
Prostate Cancer Management
(Mr P Cooke - Consultant Urological Surgeon)

Monday 13th May 2019
Oncological Treatment for Prostate Cancer
(Dr R Dandamudi – Consultant Clinical Oncologist)

Monday 1st July 2019 – RAFFLE
Male Incontinence
(Michele Miletic – Urology Advanced Nurse Practitioner)

Monday 2nd September 2019
Support for progressing Prostate Cancer
(Andrew Bagnall – Clinical Nurse Specialist/Lecturer, Compton Care))

Monday 21st October 2019 – RAFFLE
Surgical Treatment for Prostate Cancer
(Jane Boddy – Consultant Urological Surgeon)

Monday 9th December 2019
AGM and general discussion

Success of Wolverhampton PSA Screening Event

A PSA screening event held at the Molineux stadium in October this year saw men queueing out of the door to have their PSA blood test checked. A total of 445 men underwent testing with 18 men identified as needing further referral for investigations. The event was organised by the Graham Fulford Charitable Trust and the Barry Kilby Prostate Cancer Appeal. The Graham Fulford Charitable Trust in conjunction with other groups has tested to date, over 98,000 men at a cost of around £1,560,000 and has helped to identify over 1400 cancers. Watch this space for further events in 2019 in Wolverhampton.



Prostate radiotherapy can benefit some men whose cancer has spread

(Article taken from the STAMPEDE website)

Treating the prostate with radiotherapy alongside standard treatment substantially improves survival for some men with advanced prostate cancer, according to results from the STAMPEDE trial, published in The Lancet and presented at the 2018 ESMO Annual Meeting in Munich.

These findings are practice changing and will mean radiotherapy, alongside hormone therapy should become the standard of care for some men with advanced prostate cancer.

In this part of the STAMPEDE trial, more than 2,000 men with prostate cancer that had already spread beyond the prostate were randomly split into two groups:

- Group A received standard treatment (hormone therapy, plus docetaxel for those men who were recruited in 2016)
- Group H received standard treatment (hormone therapy, plus docetaxel for those men who were recruited in 2016) plus radiotherapy to their prostate.

After three years of follow-up, the researchers found that overall, there was no difference in how long men in the two groups lived, on average.

But, for the sub-group of men whose disease had spread less ('low metastatic burden') at the time of diagnosis, there was a significant benefit from radiotherapy. After 3 years, 81% of men with low metastatic burden in the radiotherapy group were still alive, compared to 73% of men in the standard treatment group. Radiotherapy also delayed the disease getting worse.

Radiotherapy did not help men whose disease had spread further at the time of diagnosis (high metastatic burden) to live longer.

The proportion of patients reporting having had severe side-effects was very similar between men who had standard treatment plus radiotherapy and those who had standard treatment alone.

Around 7,000 men are diagnosed in the UK each year with prostate cancer that has already spread beyond the prostate.

Dr Chris Parker, lead researcher of the study and based at the Royal Marsden, said: "Our results show a powerful effect for certain men with advanced prostate cancer. These findings could and should change standard of care worldwide.

"Until now, it was thought that there was no point in treating the prostate itself if the cancer had already spread because it would be like shutting the stable door after the horse has bolted. However, this study proves the benefit of prostate radiotherapy for these men. Unlike many new drugs for cancer, radiotherapy is a simple, relatively cheap treatment that is readily available in most parts of the world."

STAMPEDE is the largest prostate cancer treatment trial ever, with more than 10,000 men taking part. The trial, which continues to recruit new men, has an innovative multi-stage, multi-arm design, which was developed and run by the MRC Clinical Trials Unit at UCL. The multi-arm multi-stage or "MAMS" design, which was developed by the MRC CTU at UCL, allows several treatments to be assessed against a single control arm, and for new treatments to be added to the trial as it progresses.

Results from STAMPEDE have already shown adding two different drugs to standard hormone therapy (abiraterone and docetaxel) can improve survival for men with prostate cancer.

Max Parmar, Director of the MRC CTU at UCL, said: "STAMPEDE is changing the face of prostate cancer research because the scale and adaptive nature of the study means that a number of different treatment options can be investigated rapidly and in parallel and new treatments to be tested can be added. This is enabling scientists to get results much more quickly than they usually would. More data will come out in subsequent years, because of the innovative design of the trial. This shows us the importance of investing in more adaptive trials like STAMPEDE to help us make similar progress in the treatments of other diseases such as Alzheimers and TB."

Opening up about the mental toll of prostate cancer and how to cope with it

(Article taken from Prostate Cancer Charity website)

To mark World Mental Health Day, we're highlighting the often overlooked emotional impacts of prostate cancer. We spoke to men with the disease about their mental health challenges and ask what their, our Specialist Nurses' and your tips are for maintaining your emotional wellbeing.

It sounds obvious but can so easily be ignored: the diagnosis and treatment of prostate cancer can take a huge mental toll. From the initial shock of hearing the 'C-word' to the helpless feelings during treatment that your life is no longer in your control, the range of emotions men go through can be vast. So what can you do to help manage these difficult feelings?

Get informed, feel empowered

Rod Coverley powerfully described his suicidal thoughts after he was first diagnosed. "I'd never thought about committing suicide. I was a confident, strong, successful person," he says. "But I felt like I couldn't do anything, like someone was taking my life away from me."

In the midst of it all, he found our publications and website a lifeline, helping him feel more reassured and less isolated.

"As I read through all the information, the thoughts of me taking my own life went away because I found I was not alone," he says. "Those negative thoughts stayed with me for a long time. But I still have my life and my wife. I'm active and I'm fine."

Talking therapy and medication

For Will Trubridge, the demands of balancing a physical job with hormone therapy left him tired and susceptible to mood swings.

"I just couldn't do as much as I was used to," he says. "People at work kept offering to help me lifting stuff or doing things for me, and I found myself shouting at them to leave me alone and let me do it myself. I just wanted to be normal. Things came to a head when I had a meeting with my Director and I just started crying."

He was subsequently diagnosed with depression by his GP and given anti-depressants as well as therapy, which helped him and his wife open up about their feelings and their relationship. He also found complementary therapies, like reflexology, beneficial.

"It won't do anything for my cancer, but it certainly helps with relaxation and emotional wellbeing," he says. "And when you're emotionally strong, it's easier to cope with hardships, isn't it?"

Tell someone and don't feel guilty

Kurt Jewson also found medication and talking to a Macmillan counsellor helped – as well as learning not to feel guilty about his mental health.

"People said that I was 'fighting' cancer – I wasn't," he says. "The cancer treatment seemed pretty passive. The active fight was the depression, which I knew nothing about and had no way of coping with.

"If you feel like I did then it's OK. Don't panic and don't fight it. If you fight it, you end up depressed and guilty. Be brave and tell someone. A problem shared is a problem with a bit knocked off."

Talk to others and get support

It can be good to hear others' experiences of dealing with prostate cancer, and many men – like Kurt – say they find it cathartic to share their own. Our Online community is a great place to talk with others in the same situation as you, or you can talk to one of our trained volunteers who have experience of the disease through our One-to-one peer support service.

Prostate cancer spit test is trialed

(Article taken from BBC News website)



A spit test to detect men at increased risk of prostate cancer has started early trials.

The new DNA test looks for high-risk genes that are thought to affect one in every 100 men. Three hundred men are taking part in the trials, from three London GP surgeries.

Developing better diagnostic tests that could be used as part of a nationwide screening programme is a research priority for prostate cancer.

At present, there is no single, reliable test for prostate cancer. The PSA blood test, biopsies and physical examinations are all used. But the PSA can give false positives and sometimes misses more aggressive cases.

The new DNA test was created by a group of international scientists based at the Institute of Cancer Research (ICR) in London. They studied more than 140,000 men and identified 63 new genetic variations that can increase the risk of prostate cancer.

The DNA test combines those variants with more than 100 others previously linked to prostate cancer. Ros Eeles, professor of oncogenetics at the ICR, said the study was "very significant".

"By looking at the DNA code of tens of thousands of men in more depth than ever before, we have uncovered vital new information about the genetic factors that can predispose someone to prostate cancer, and, crucially, we have shown that information from more than 150 genetic variants can now be combined to provide a readout of a man's inherited risk of prostate cancer."

Only those men found to be at higher risk of prostate cancer would then be scanned and have a prostate biopsy, so researchers hope it could prevent unnecessary procedures.

"It could have a substantial impact on how we actually manage those at increased risk because if you find the disease earlier it's much easier to treat it and much more easy to cure," says Prof Eeles.

The trial will be expanded to 5,000 men next year.

Prof Paul Workman, chief executive of the Institute of Cancer Research, said the study also provided important information about the causes of prostate cancer and the potential role of the immune system "which could ultimately be employed in the design of new treatments".

The study is published in the journal Nature Genetics and was funded by the the National Cancer Institute in the US, with additional support from the European Research Council, Cancer Research UK and Prostate Cancer UK.

Dr Iain Frame, director of research at Prostate Cancer UK said: "This new research could help men to understand their individual genetic risk of prostate cancer, which could prompt them to speak to their GP about the disease.

"Given that one in eight men will be diagnosed with prostate cancer in their lifetime, we urgently need more accurate diagnostic tests which are suitable for use in a nationwide screening programme."

Carl Alexander from Cancer Research UK, said the study was "an exciting example" of how research can find clues in our genes to help us uncover those more likely to develop the disease.

"The next steps should be to understand how this research can be developed into tests which could identify men who might be more likely to develop aggressive cancers, and how this could be rolled out to patients."

PROMIS Study Results

Diagnostic accuracy of multiparametric MRI and TRUS biopsy in prostate cancer.

(The Lancet, volume 389, issue 10071, p815-822, February 25, 2017)

Men with high serum prostate specific antigen (PSA) usually undergo transrectal ultrasound-guided prostate biopsy (TRUS-biopsy). TRUS-biopsy can cause side-effects including bleeding, pain, and infection.

A pathway with imaging as a triage test to decide which men with an elevated PSA go on to biopsy might both reduce unnecessary biopsy and improve diagnostic accuracy. Multi-Parametric Magnetic Resonance Imaging (MP-MRI) provides information on not just tissue anatomy but also tissue characteristics such as prostate volume, cellularity, and vascularity. There is some evidence that MP-MRI tends to detect higher risk disease and systematically overlooks low-risk disease, which makes it attractive as a potential triage test.

Using MP-MRI to triage men might allow 27% of patients avoid a primary biopsy and diagnosis of 5% fewer clinically insignificant cancers. If subsequent TRUS-biopsies were directed by MP-MRI findings, up to 18% more cases of clinically significant cancer might be detected compared with the standard pathway of TRUS-biopsy for all.

The main findings of this study shows that MP-MRI, used as a triage test before first prostate biopsy, could reduce unnecessary biopsies by a quarter. MP-MRI can also reduce over-diagnosis of clinically insignificant prostate cancer and improve detection of clinically significant cancer.

Unexpected surge in men getting checked after Fry announcement highlights need for national screening programme

(Article taken from Prostate Cancer Charity website)

NHS England Deputy Chief Executive Matthew Swindells reportedly stated that Stephen Fry's prostate cancer diagnosis had led to a surge in referrals to NHS services which contributed to missed waiting time targets.

Swindells revealed that the percentage of patients being treated within the 62-day wait target has dropped significantly in the last couple of months but that the reasons for this are complex. He suggested that this was possibly due to an extraordinary spike in demand for diagnostic services and treatment for a number of cancers, particularly urological cancers such as prostate, which may have been driven by the media coverage of Stephen Fry's announcement of his prostate cancer diagnosis.

There have been increases in referrals to a number of cancer specialties, particularly in urology, which has seen an unprecedented 15 per cent jump this year. As supply has struggled to keep up with demand, this has had a knock-on effect on the waiting targets.

The 62-day target refers to the aim that 85 per cent of patients with suspected cancer who are urgently referred to a specialist by their GP should start definitive treatment within 62 days. NHS England figures from April to June, published last month, show 80.8 per cent of patients with suspected cancer started treatment within 62 days of being urgently referred by a GP.

Author, presenter and actor Stephen Fry publicly announced in February that he had been diagnosed and treated for aggressive prostate cancer to his 13 million followers on twitter. This gained widespread coverage in mainstream and social media. It followed our announcement earlier that month that prostate cancer has now become the third biggest cancer killer in the UK.

Heather Blake, Director of Support and Influencing at Prostate Cancer UK, responded to the story: "Since the beginning of 2018 we have seen an unprecedented amount of public interest in prostate cancer, following the announcement that it is now the third biggest cancer killer in the UK, and high profile individuals such as Stephen Fry and Bill Turnbull sharing their experience of the disease. It is likely that this increased awareness will have had an impact on the number of men at risk of the disease going to their doctor to discuss prostate cancer and subsequently sent for further tests.

"It is a good thing if awareness of this killer disease is increasing, and more men are taking control by discussing it with their GP. However, this reinforces the need to find diagnostic tools which are reliable enough to be used as part of a national screening programme for prostate cancer, something we are committed to doing through our research programme. This would not only provide more certainty around diagnosis for men and save more lives, it would also make it easier for NHS providers to plan resource around it."

Thanks to our supporters, we have been able to invest millions into ground-breaking research to improve diagnosis, leading to breakthroughs such as the use of mpMRI scans to reduce unnecessary biopsies.

We are committed to leading the creation of a screening programme for prostate cancer – a key part of our strategy to halve the expected number of deaths from prostate cancer by 2026. Through our research, we are working towards finding the right tests to make this a reality for men.

